

Gilbert's Syndrome

Gilbert's Syndrome is named after a French Gastroenterologist, and it's sometimes called 'Unconjugated hyperbilirubinaemia'.

Gilbert's Syndrome is thought by some scientists to be inherited and it is caused by a mutated gene UDP - glucuronosyltransferase), which leaves those affected with less of the related enzyme (called UGT for short). An enzyme is a chemical substance in your body that causes a chemical reaction to happen. Lack of this particular enzyme, UGT, is the key to what happens in our body and results in the symptoms we can experience:

The Gilbert's Syndrome Story

If you're like many people diagnosed with Gilbert's Syndrome, you've been on a long journey to find out what's wrong with you, visiting doctor after doctor and coming up with nothing. And then one day, a doctor tells you that you have Gilbert's Syndrome but that it's not the cause of your problems because their desk reference says that there are no symptoms. At that point the doctors usually tell you that all your symptoms are probably due to stress or depression.

There are [several scientific studies](#) examining the many and varied effects of Gilbert's Syndrome, but apparently they haven't found their way into the desk references yet. The fact is that there is a striking degree of similarity in the symptoms suffered by those with Gilbert's Syndrome, and these symptoms can be incredibly disruptive to one's life. Luckily, it is not life threatening. But this may also be the reason it doesn't get the attention it deserves.

Symptoms

Frequently Reported: fatigue, tiredness, irritability, calcium spots, brain fog, headaches, poor memory, dizziness, depression, irritability, anxiety, nausea, loss of appetite, irritable bowel syndrome (IBS), stomach pain & cramping, liver/gallbladder pain, abdominal pain, tremors, itchiness, jaundice

Commonly Reported: insomnia, difficulty concentrating, panic attacks, hypoglycemic reaction to foods, intolerance to carbs, food intolerances, alcohol intolerance, loose stools / diarrhea, abdominal bloating or swelling, breathlessness or labored breathing, heart palpitations, aching muscles / body ache, joint pain, numbness & tingling, weakness, chemical sensitivity, weight loss, hypoglycemic-like reactions to food, lump in the throat, feeling constantly sick

Sometimes Reported: difficulty finding the right words, feeling drunk, vomiting, intolerance to fatty foods, strong hangovers, acid reflux, excessive thirst, chest pain, muscle twitches, cold hands and feet, environmental allergies, swollen lymph nodes, toxic feeling, bitter or metallic taste in the mouth, eye pain

Occasionally Reported: waking panic attack, mood swings, feeling antisocial, intolerance to drugs, constipation, pale stools, indigestion, back pain, dry skin, feeling cold, low body temperature, pale skin, low weight, night sweats, excessive sweating, poor immune system, sore or dry throat, light sensitivity, bloodshot eyes

Many of these I have connected either directly to Gilbert's Syndrome or via effects caused by GS. As to the rest, I'm investigating the following possibilities:

Symptoms of our liver's reduced ability to do the cleaning it's designed to – *jaundice, nausea, fatigue, 'brain-fog', depression, shakiness, bowel complaints, vomiting, difficulty concentrating*, are experienced in varying degrees by those with GS.

It seems that certain activities may make these symptoms worse, by placing further stress upon the liver. *Missing meals, lack of sleep, vigorous exercise, illness and stress* can all bring on the symptoms.

Most important in keeping your liver functioning as well as possible is maintaining stable blood sugar levels. This is because the enzyme we don't have much of uses sugar to help get rid of the toxins it is supposed to deal with. We can also fool the liver into making more of the

enzyme by eating certain foods and diet plays an important part in managing GS.

At present there isn't a clear link between all the processes involved, or even that GS is actually hereditary. AGS hopes that, through funding research and creating a higher profile for GS, we can better understand and treat the symptoms of Gilbert's Syndrome.

1 Treatment and management of GS.

1.1

1.2 Diet and supplements:

1.2.1 What could make us feel worse:

Alcohol - People with GS seem sensitive to alcohol to differing degrees. The best advice is to be aware that it can cause stress to your liver and see how much or little your body is happy to process.

Fatty foods - digestive problems seem common in GS and some people find fatty foods put a lot of stress on their digestive system.

Sugary foods and **refined carbohydrates** - these mess with the body's energy levels, and if you're suffering with fatigue then these won't help balance your energy. Plus sugar can impair your liver's ability to detoxify.

Other suspects include - fluoride, peppermint, vanilla, menthol and the B vitamin niacin (on its own, but ok with other B vitamins)

Artificial sweeteners - can cause an increase in the '*brain-fog*' experience.

1.2.2 What could help:

Protein - Raising the protein proportion of their diet has provided raised energy levels for some GS sufferers. Oily fish may be particularly effective as it could also enhance the removal of the fat-soluble bilirubin from the body.

Broccoli, walnuts, blueberries, avocados, cabbage, cauliflower, eggs - a combination of natural sulphur compounds and those containing glutathione (the most powerful internal antioxidant and liver protector) will aid the breakdown of toxins and chemicals.

Supplements of glycine, glutamic acid and cysteine also produce glutathione and thus aid the detoxification in the phase 2 pathways.

Taurine plays a major role in good liver function via detoxification.

Turmeric has been shown to increase the glutathione and glucuronyl transferease enzymes important for detoxification.

Milk Thistle is used by many people with GS, and has been used for hundreds of years as a herbal remedy for liver disorders and depression (which medicinal herbalists often link).

Carrots and beetroot are fantastic detox aids.

Methionine, an amino acid, activates the phase 2 pathways.

Dandelion tea can stimulate liver function.

Royal Jelly is taken by some people with GS, who have found it beneficial for their energy levels.

1.3Lifestyle:

Exercise - Sudden exertion can cause fatigue. Some have found that gently increasing fitness levels over time results in an all round improvement in energy and an ability to exert oneself more than previously, without the same consequences. It's good advice to everyone, GS or not, to exercise for at least 30 minutes every day.

Sleep - get it if you can. At least 8 hours a day is recommended by some to put you back on your feet if you're really feeling the symptoms. Lack of sleep stresses the liver functions and over time can produce GS symptoms. A nap after lunch can help preserve energy levels for the evening, if you find the end of the day a struggle.

Anxiety, stress and depression - a complex area. Anecdotally people have suffered socio-phobia and anxiety attacks after experiencing GS symptoms. The reverse is also true, and psychological stress and unhappiness can have a physical response in stressing the liver function and cause GS symptoms. There are also many mental health issues raised by having to deal with a potentially new lifestyle in order to manage your GS symptoms. You should always seek help from your doctor if you are suffering from depression. There are many ways of managing unhappiness, anxiety and stress, and many organisations giving better advice than there is space for here. Meditation, cognitive behavioural therapy, yoga, and other forms of dealing with your frame of mind could be worth trying.

Work, rest and play - to sum up, get the balance right for you as you are right now. Don't feel like you're 'giving in' or a 'failure' for taking sensible decisions to change your lifestyle so that you can feel less ill. The less ill you feel the better you can live. But find your balance - it may take years, and it may change with your circumstances.

Maybe a part time job is right so you can spend more time resting and have more energy for a social life, which is good for your mental health. Maybe your job is all you can do during the day, and socialising in the evening is a write-off - instead you could have lunch with friends, and see them during the day at weekends instead. Maybe you can't run a mile right now, but you could walk half a mile today, and a mile in 6 months. Sometimes you'll be forced to pack in more than you can handle, and you'll feel ill for a while. But that's ok too. Just get the balance to where you're happy with it, and don't forget that looking after your mental health is as important as your physical health. In fact the two are inextricably linked.